



A Comprehensive Guide for COVID-19 Longhailers and Physicians: The PASC Master Document

This "Master Document" was created as a guide to help Longhailers and their physicians work as a team in an attempt to get the patient back to good health and regain quality of life. A year into the Pandemic, we are still struggling to curb it and still lack understanding in Post-Covid Syndrome now being referred to as Post-Acute Sequela of Covid-19. There are now millions of Longhailers in the United States alone and millions more around the world. This document has been thoroughly built over months and is updated multiple times a month. It is imperative to save the link to this document as updates are saved automatically to google, but if you print it or save it to your desktop, you will only have access to the version you downloaded. Everything in this document is based off findings in Longhailers only. Included information has been vetted and is known to commonly and frequently be found and occur in Longhailers. Longhailers are facing extreme medical gaslighting and are having every aspect of life impacted by their illness. There are a lot of statements, tips and guidance related to these things within. Longhailers, please use the information within to advocate for yourself, educate yourself and those you are surrounded by. Physicians and researchers, please use the information within to become familiar with PASC, longhailer experiences and needs. We are easily approachable and encourage collaboration, so please do not hesitate to contact us.

The Covid-19 Longhailer Advocacy Project is a group for Longhailers, those with chronic symptoms and illness for over a month. Most Longhailers in this group are over 10 months post infection (as of 2/2021). Many have developed new, chronic and potentially lifelong health conditions triggered by Covid-19. Approximately 90% were never hospitalized and had mild to moderate infection and now report their health issues being worse than acute infection and as debilitating, altering life as they knew it.

Our mission is advocacy, education and support. We advocate for legislation to protect and help Longhailers and for medical care and recognition. We provide education to our members, to health care providers and researchers and will fight to prevent and stop the gaslighting and lack of knowledge on PASC prohibiting physicians from providing their patients quality care. We provide support for members who often have no one else to turn to besides other Longhailers going through the same experience. This is a safe place, this is a place for change and for hope, but we need all of you to support our efforts and show up when asked to.

The Covid-19 Longhailer Advocacy Project is a Co-Founder of the Long Covid Alliance with Solve ME and the Global Pandemic Coalition. You can visit longcovidalliance.org for more information on who we are, what we have done, and what we are working on, including NIH recommendations and funding agendas. We are here to help, create a path forward to healing, to advocate for all of you, educate the world and provide the support you need. Please feel free to message our admin or moderators with any questions, especially media requests. We look forward to continuing to be the leading Long Covid Advocates and paving the way for Longhailers.

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What Should Physicians be Doing

Listen to and validate your patient.	This is probably the most important thing you can do. Longhaulers have been ignored, dismissed and let down for months. Physicians are not listening to them, do not believe them, tell them it's all in their head, diagnose them with anxiety, tell them this is normal and give it time, or that they have never heard of anyone else having these issues, or this severity of issues. <u>DO NOT BE THAT DOCTOR.</u> Plan ahead for more time with this patient to discuss a complex history post-COVID. Understand Longhaulers are not just living through a pandemic, but make up the pandemic. Longhaulers are seeking your help and guidance. Give them the time and attention deserved.
Offer your patient testing.	There is pre-covid medicine and post-covid medicine. Anything goes with this virus. Everything listed in this document is being found and diagnosed in Longhaulers in very large numbers and included for a reason. Just because you haven't heard of or seen it yet, doesn't mean it is not a possibility. Just because there is no publication out on it yet does not mean it's not valid. We are 5-6 months ahead of all publications and information coming out. Listen. You have the potential to curb a life-long issue if corrected now. Take action. There are plenty of ICD-10 codes now out to cover testing for suspected covid related issues!
Take the time to review your patients documents.	All patients are encouraged to heavily document their covid experience and be able to produce this information and evidence at appointments. Many Longhaulers are suffering extreme medical PTSD from gaslighting. They are encouraged to pre-load their physicians before the appointment. Your staff MUST ask patients if they are Longhaulers and alert you to that with enough time that you can review this patients issues they are preloading you with prior to the appointment. Does it take extra time from you? YES. Is it your obligation to provide quality care? YES. Longhaulers are waiting 3+ months for appointments and eager for answers, validation and solutions when they finally arrive. Preloading not only helps with the patient's brain fog and memory issues in addition to the medical PTSD, but it also gives you the opportunity to research and consult other physicians prior to the appointment so that the appointment goes smoothly and can be focused on solutions rather than a review of the past year of the patient's life. We are coming for solutions. Help.
Research and educate yourself.	To reiterate the above, patients are coming to you for solutions. If you are not fully up to date on Longhaulers, Post-Covid Syndrome, and the other illnesses listed in this document, you need to do what you need to do to get there. There is no excuse to be lazy or give patients the run around, or blame their issues on anxiety because an ego gets in the way of simply saying "I don't know". If you really don't know, say that and then follow up with "but I will be spending a lot of time trying to learn more about it for our next visit". Under the resources section in this document, go to studies and review the completed studies by this group and body politic. Then go and watch some of the webinars or review articles through JAMA and BMJ. You can even join the Facebook group to read through patients' stories and experiences. We encourage this.
Share information to educate your physician friends and colleagues.	Physicians who have a patient that is a Longhauler are not talking to their friends or colleagues about their findings (obviously while honoring HIPAA). These discussions are needed since there are limited publications coming out on Longhaulers. Start some in office case studies and put out small publications or white papers amongst your peers. This is an emergent, time sensitive situation for us and we cannot wait years for research to come in. Be proactive. Additionally, the patients physicians are not working as a team and talking to one another. My cardiologist should be talking to my pulmonologist and rheumatologist and so on about my issues and plan of care. They should be brainstorming together, bouncing ideas off one another, discussing other patient findings and piecing together the puzzle. When no one talks to one another, we go in circles and everyone is thinking and doing something different pointing the finger back at another specialty you just came from. Collaboration is key.

Gold Standard Testing for Every Patient

1. Cardiac MRI: Myocarditis = top cardiac issue <https://jamanetwork.com/journals/jamacardiology/fullarticle/2768916>
2. Follow up Cardiac MRI w/ ECHO & Stress ECHO
3. Chest CT over X-Ray
4. Brain MRI w/ contrast
5. Bloodwork: Inflammatory, cardiac, clotting and functional markers
6. Autonomic and Neurological testing

The Eye-Popping Data on the Number of Longhaulers , Secondary Issues and Costs

https://docs.google.com/document/d/10-e7ClwcobAA7cSCRvSXXmBNtEa5n-6V_j5u132wogA/edit

Survey 3 “longhaulers experiences and needs” which focuses on effects on daily life

<https://docs.google.com/document/d/1uKX3dCdUgeVjlwaOAJilGa8HKK08c1ISU9vBQeVY0yc/edit>

Body Politic, Patient Led Research Team

<https://www.medrxiv.org/content/10.1101/2020.12.24.20248802v2.full-text>

InCellDX Longhailer Index Assay

<https://www.biorxiv.org/content/10.1101/2020.12.16.423122v1.full.pdf>

Covid Longhaul Groups discuss the Longhailer Index and its Significance

<https://www.youtube.com/watch?v=bSObeeceZos&t=4s>

Dr. Fauci discusses Long Covid, gives it a name, recent study findings 2/25/21- min 20

https://l.facebook.com/l.php?u=https%3A%2F%2Fyoutu.be%2FhsU3wLKzFJ0%3Ffbclid%3DIwAR1lxASfGft9Xsglv60YpHAYAbiPkWXCTsHVPU7d4bkiZEgU72oKIEzjvYo&h=AT1ac7xVlbV7Gvd7OECSfTQy_LiGSCxJW5y48ldsCb07anIUiuL-gMvRn6QY6EUbEwav5aTARWLVpSsdK_FZMWMCCt0WSbBpQ8bdlsrpNUVGJcTzavcrUg-Ym8Kh-E0nChEqznFDhdEHqR9nJ_o



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Diagnostic Testing by Specialty

Pulmonary	Cardiac/ Cardiovascular	Rheumatology
• Chest CT with and without contrast • Chest X-Ray • Pulmonary Function Test (not just spirometry) • Appropriate blood work	• Echocardiogram • Cardiac MRI • 12 Lead EKG • Tilt Table Test • Stress Test (if medically safe to do) • Appropriate blood work	• MRI (on symptomatic area, suspicion for RA) • Musculoskeletal Ultrasound • Biopsy for Sjogren's Syndrome • Appropriate blood work
Neurological	Gastroenterology	ENT
• Brain MRI with contrast • Brain CT • Angiography • EEG • EMG • Neurologic exam • Neuropsychological exam • CSF analysis • Autonomic Function Test • Biopsy for Small Fiber Neuropathy • Appropriate blood work	• Colonoscopy • Endoscopy • Abdominal ultrasound • Gastric empty study • Biopsy • Appropriate blood work	• Basic Exam: ears, nose throat (may be referred to allergist) • Throat Endoscopy (may be referred to specialists) • Hearing Test • MRI with contrast • Biopsy of lymph nodes • Laryngoscopy • Phonatory assessment
Hematology	Dysautonomia Specialist	Infectious Disease
• Ultrasound • MRI • CT • Appropriate blood work	• Autonomic function testing (tilt table test, qsart, gastric empty study, thermoregulatory sweat test, urinalysis and bladder function test, ultrasound) • Appropriate blood work	• MRI • Chest CT • X-Ray • Spinal Tap • Appropriate blood work
Hepatology	Urology	Ophthalmology
• Ultrasound • MRI • CT • Biopsy • Appropriate blood work	• Urodynamics study • Ultrasound • Pelvic Exam (women) • Urinalysis	• Basic Vision Test (pupils, retina, slit lamp test, tonometry, age related macular degeneration, cataracts, optic nerve) • Optic Nerve - may need to consult a neuro-ophthalmologist
Dermatology	Endocrinology	Immunology/ Allergist
• Culture • Biopsy • Hair loss solutions	• Ultrasound • Appropriate blood work	• Allergen, MCAS testing • MRI • CT • Appropriate blood work



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Diagnostic Labs

Test	Indication	Test	Indication
CMP & CBC	Basic blood work: Anemia, leukemia, inflammatory process, electrolytes, kidney and liver function, and acid/base balance	Amylase	Inflammation of pancreas & salivary glands (mumps), biliary tract disease & bowel obstruction
BNP & Pro BNP	Indicator of congestive heart failure, left ventricular hypertrophy, acute MI, hypertension, pulmonary hypertension, acute lung dysfunction,, chronic renal failure, cirrhosis	Lipase	pancreatitis
Troponin I & T	Acute coronary syndrome, MI, Cardiac Predictor for ACS	Lactate Dehydrogenase	MI, liver disease, pernicious and megaloblastic anemia, pulmonary emboli, malignancy, musc dyst.
Homocysteine	Risk factor for cardiovascular disease, b12 and folic acid deficiency	ALT	Liver disease, heart muscle damage
D-Dimer	Fibrinolytic activation and intravascular thrombosis (clots)	Amylase	Inflammation of pancreas & salivary glands (mumps), biliary tract disease & bowel obstruction
Factor 5 Leidein	Increased risk of venous thrombosis (clots)	Lipase	pancreatitis
CMP & CBC	Basic blood work: Anemia, leukemia, inflammatory process, electrolytes, kidney and liver function, and acid/base balance	Lactate Dehydrogenase	MI, liver disease, pernicious and megaloblastic anemia, pulmonary emboli, malignancy, musc dyst.
BNP & Pro BNP	Indicator of congestive heart failure, left ventricular hypertrophy, acute MI, hypertension, pulmonary hypertension, acute lung dysfunction,, chronic renal failure, cirrhosis	AST	MI, hepatitis, liver necrosis, cirrhosis, liver metastasis
Troponin I & T	Acute coronary syndrome, MI, Cardiac Predictor for ACS	CO2	Changes in body acid balance
Homocysteine	Risk factor for cardiovascular disease, b12 and folic acid deficiency	Lipid Panel	Cardiovascular disease, ischemic event, atherosclerosis, metabolic syndrome,
Iron & Total Iron Binding Capacity	Iron deficiency anemia, hemochromatosis	Complete Urinalysis	Infection, kidney and liver function/ disease
Iodine	Thyroid hormone production, adequate dietary intake	Hemoglobin A1C	Diabetes
Folate	B12 deficiency, small intestine damage	Phosphate	Hypoparathyroidism, sarcoidosis, vitamin d deficiency, renal tubular acidosis, hypervitaminosis D, Milk-Alkali syndrome



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Ferritin	Hypochromic and microcytic anemia, Iron deficiency anemia, iron overload	Total Protein and Protein Electrophoresis	Protein abnormalities including monoclonal gammopathies
B1 (thiamine)	Associated with chronic illness, beriberi, branched chain amino acid and carbohydrate metabolism, irritability, apathy, generalized weakness.	TSH	hypothyroidism
B2 (riboflavin)	Metabolism of fats, proteins and carbohydrates, mucocutaneous lesions of the mouth and skin, corneal vascularization, anemia, personality changes	T4 Free	Hyperthyroidism, hypothyroidism, graves disease
B3	Reduces heart attack and slows narrowing of arteries.	Catecholamines	Hypertension, orthostatic hypotension
B6	Metabolism of protein, fat and carbohydrates, creation of red blood cells and neurotransmitters, mood changes, skin rashes, cracked and sore lips, sore tongue, weakened immune function, low energy, tiredness, tingling and pain in hands and feet, seizures, high homocysteine	Acetylcholine Receptor Ganglionic AB	Autoimmune Autonomic ganglionopathy, paraneoplastic AAG, autonomic neuropathy, autonomic nervous system dysfunction or failure
B7 (biotin)	Transfers carbon dioxide in the metabolism of fat, carbohydrates and proteins by functioning as an enzyme cofactor, seborrheic dermatitis, alopecia, myalgia, hyperesthesia, conjunctivitis	Angiotensin-1 Converting Enzyme	Sarcoidosis, gaucher's disease, lymphangiomyomatosis
B12 (cobalamin)	Anemia, production of red blood cells, proper functioning of nervous system, numbness, tingling, fatigue, weakness, cognitive difficulties, memory loss, balance problems, swollen tongue	Vascular Endothelial Growth Factor	Encourages growth of new blood vessels. Tumors, Cancer, leaky blood vessels, showing up in covid patients as covid attacks the endothelium
Vitamin A (retinol)	Vision, growth, cell function, renal failure, fat malabsorption, bone fractures	Tryptase	Anaphylaxis, acute allergen challenge, mastocytosis, Mast cell activation syndrome
Vitamin C	Connective tissue metabolism, drug metabolism systems, mixed-function oxidase systems, impaired formation of matured connective tissue, bleeding into the skin, weakness, fatigue, depression	24 hour Prostaglandin	Mast Cell Activation Syndrome
Vitamin D (25-hydroxy total immunoassay)	Poor absorption of vitamins, bone disease, hypercalcemia	IGA	Monoclonal iga myeloma, respiratory and gastrointestinal infections and malabsorption, iga deficiency, ataxia telangiectasia
Vitamin E (tocopherol)	Neuropathy, interstitial malabsorption, bowel or pancreatic disease, chronic	Myasthenia Gravis Panel 3	Myasthenia gravis, skeletal muscle weakness and fatigability, thymoma,

	cholestasis, celiac disease, cystic fibrosis, interstitial lymphangiectasia		thymic hyperplasia
Vitamin K	bleeding	Striated muscle AB w/ reflex to titer	Myasthenia Gravis
Zinc	Wound healing, immune function	Phospholipase A2 Receptor AB, ELISA	Primary membranous nephritis (autoimmune disease)
B2 (riboflavin)	Metabolism of fats, proteins and carbohydrates, mucocutaneous lesions of the mouth and skin, corneal vascularization, anemia, personality changes	Sars-Cov-2 AB	Detection of previous covid infection
B3	Reduces heart attack and slows narrowing of arteries.	Prostaglandin E2	Inflammation, arthritis, fever, endometriosis, tissue injury, pheochromocytoma, VIP producing tumors, variety of cancers
Melatonin	Impaired central nervous system function, orthostatic hypotension, sleep disorders, depression, stress, schizophrenia, immunological disorders	IGA	Monoclonal iga myeloma, respiratory and gastrointestinal infections and malabsorption, iga deficiency, ataxia telangiectasia
ANA Choice Screen	Rheumatic disease, lupus, connective tissue disease, sjogren's syndrome, scleroderma, polymyositis, crest syndrome, neurologic SLE	Pancreatic Elastase-1	Measures exocrine pancreatic function
Rheumatoid Factor	Collagen vascular diseases such as SLE, rheumatoid arthritis, scleroderma, sjogren's syndrome, and leprosy, tuberculosis, syphilis, malignancy, thyroid disease, the elderly	Parietal Cell AB W/ Reflex Titer	Pernicious anemia
Intrinsic Factor Blocking AB	Binds to vitamin b12, pernicious anemia	SM AB	Highly specific for systemic lupus erythematosus
DNA AB (DS) Crithidia, IFA	Active systemic lupus erythematosus and approximately 20% of patients with mixed connective tissue disease	SM/RNP AB	Found in patients with mixed tissue disease (having features of SLE, scleroderma and polymyositis)
NK Cell Function	CFS		

Continue to Long Hauler Index Below

Longhailer Index by Dr. Bruce Patterson: Findings

<https://www.biorxiv.org/content/10.1101/2020.12.16.423122v1> <https://covidlonghailers.com/>

IL-2	significantly elevated, regulates the activity of white blood cells	IL-10	significantly elevated	CCL3	significantly elevated, involved in acute inflammatory state, recruits and activates polymorphonuclear leukocytes	T-Cell	No evidence of exhaustion
IL-4	significantly elevated, produced by mast cells and induced differentiation of naive helper T cells	IL-13	-	CCL4	significantly decreased	B-Cell	Significantly elevated
IL-6	significantly elevated, secreted by macrophages and stimulate the production of neutrophils in bone marrow	IFN-γ	significantly elevated, produced by NK and NKT cells as immune response	CCL5	Significantly elevated regardless of disease severity	CD14	Significantly elevated
IL-8	-	sCD40L	-	TNF-α	-	CD16	Significantly elevated
				GM-CSF	significantly decreased, produces neutrophil proliferation and maturation	Monocytic Subset	Significantly elevated

New ICD-10 codes for the following COVID-19-related illnesses:

Z11.52 Encounter for screening for COVID-19	M35.81 Multisystem inflammatory syndrome
Z20.822 Contact with and suspected exposure to COVID-19	M35.89 Other specified systemic involvement of connective tissue
Z86.16 Personal history of COVID-19	J12.82 Pneumonia due to COVID-19
U08.9 Personal history of Covid-19, unspecified **confirmed or PROBABLE** that influences the person's health status	U10.9 Multisystem inflammatory syndrome associated with COVID-19, unspecified **temporarily associated with COVID-19: Cytokine storm, kawasaki-like syndrome, pediatric inflammatory multisystem syndrome with COVID-19, MIS-C. Excludes mucocutaneous lymph node syndrome (kawasaki M30.3)**
U09.9 Post-COVID-19 condition, unspecified **allows the establishment of a link with COVID**	

What We are Seeing in Longhaulers

There are 6 comorbidities heavily intertwined in general and are now being very frequently found and diagnosed in LH's: Postural Orthostatic Tachycardia Syndrome, Myalgic Encephalomyelitis/ Chronic fatigue Syndrome, Autoimmune Disease, Fibromyalgia, Small Fiber Neuropathy and Mast Cell Activation Syndrome. Two other genetic conditions to be noted are the prevalence of Mixed Connective Tissue Disorders (mostly Ehlers-Danlos Syndrome) and the MTHFR gene mutation.

Dysautonomia (Dysregulation of the Autonomic Nervous System). The most common forms being diagnosed in Longhaulers are POTS -Postural Orthostatic Tachycardia Syndrome, OI-Orthostatic Intolerance and OH-Orthostatic Hypotension. With very limited physicians experienced with Dysautonomia, physicians must take it upon themselves to educate themselves about Dysautonomia, its multiple forms, how to assess for it and how to treat it. Physicians must stop dismissing patients and telling them it is psychosomatic or anxiety.	Diagnosis: Cardiologist, Electrophysiologist, Neurologist, Dysautonomia Specialist. Physicians should recognize autonomic dysfunction by looking at the whole patient. The signals of autonomic dysfunction to look for are: orthostatic intolerance (abnormal HR, BP or symptoms with standing), GI Dysmotility, Bladder Dysfunction, Abnormal Sweating, Dry Eye/ Mouth, Temperature Sensitivity, Flushing, ED in males. Tests: Tilt Table Test-TTT, Orthostatic testing, ECG, Sweat Tests, Symptoms review, Vascular Integrity Test. A recent patient lead survey of 1,196 in Longhauler's (Oct 2020) showed 1 in 3 Longhaulers had developed Dysautonomia. For Patients: http://dysautonomiainternational.org/page.php?ID=36 For Physicians: http://dysautonomiainternational.org/page.php?ID=38 Find a Specialist: http://dysautonomiainternational.org/map.php?SS=3 Education Materials: http://dysautonomiainternational.org/page.php?ID=95 Post-Covid Dysautonomia Webinar https://vimeo.com/459746130
POTS Symptoms You cannot have POTS and OH. These are mutually exclusive diagnoses based on internationally accepted diagnostic criteria. BP drops in 1/3 of POTS patients during tilt, but not to the degree of meeting the OH criteria. BP drops in POTS patients who have overlapping NCS which can be distinguished. Because only 1/3 of POTS patients have a drop in BP, do not let your provider tell you it's not POTS because your BP didn't drop, it doesn't in 2/3rds.	Orthostatic tachycardia, palpitations, shortness of breath, lightheadedness/ presyncope, GI motility (33% too fast or slow), nausea, sicca, bladder dysfunction, exercise intolerance, sensitivity to heat or cold, sensitivity to light/ sounds, migraine, orthostatic headaches, profound fatigue, weakness (even with normal emg), tremulousness, dependent acrocyanosis, flushing, increased allergies & sensitivities, trouble concentrating, altered sleep phases, esophageal dysmotility, peripheral neuropathy, chest pain, shortness of breath, hypovolemia, impaired sweating, iron storage deficiency, normotension or hypertension. 85% of POTS patients are female. 50% of POTS patients developed POTS after an infection. - POTS patients have a similar quality of life as patients with CHF, COPD, and on end stage dialysis. 25% of POTS patients are so disabled they are unable to work.
OI Symptoms	Altered vision, anxiety, exercise intolerance, fatigue, headache, palpitations, hyperpnea, lightheadedness, sweating, tremulousness, weakness, nausea, neurocognitive deficits, pallor, sensitivity to heat, sleep problems, vasomotor symptoms.
OH Symptoms	Lightheadedness, blurry vision, weakness, fainting, confusion, nausea, hypotension



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ME/CFS

Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome is a complex and debilitating multi-system, chronic disease with a serious impact on one's quality of life. ME/CFS typically occurs post viral infection.

The severity of ME/CFS varies greatly from patient to patient, with some people able to maintain fairly active lives. For others, ME/CFS has a profound impact. About 25 percent of people with ME/CFS are housebound or bed bound as a result of their illness. For many, there is often a pattern of relapse and remission. Most symptoms are invisible to others, which makes it difficult for family members, friends and the public to understand the challenges of the disease.

Main Page: <https://solvecfs.org/>

Patient and caregiver information:

<https://solvecfs.org/research/patient-and-caregiver-resources/>

Become an advocate/ what's in the works:

<https://solvecfs.org/advocacy/>

Medical Education and Awareness:

<https://solvecfs.org/medical-education-and-awareness/>

US ME/CFS Clinician Coalition Website

<https://mecfsciniciancoalition.org/>

Batemanhorne Center <https://batemanhornecenter.org/>

CDC <https://www.cdc.gov/me-cfs/index.html>

<https://askjan.org/disabilities/Chronic-Fatigue-Syndrom>
e.cfm?csSearch=2501332_1

Diagnosis: Infectious Disease, Primary Care, Rheumatology. Criteria: substantial impairment in function accompanied by fatigue, post exertional malaise, unrefreshing sleep, and either cognitive impairment or orthostatic intolerance for >6 months. Other common symptoms are pain, flu-like symptoms including sore throat and tender lymph nodes, sensory sensitivity, and gastrointestinal symptoms. Symptoms can be made worse by mental or physical exertion or by upright posture similar to POTS.

Tests: There is no diagnostic test for CFS but your doctor will order Complete blood count to help rule out leukemia, anemia, and lupus, Lyme disease, thyroid function, blood chemistry to make sure sugar levels and other measures of health don't point toward another possible cause, such as metabolic syndrome, and urine tests.

- Between 836,000 and 2.5 million Americans suffer from ME/CFS[2] and estimates vary from 17 – 24 million people with ME/CFS worldwide. Although research has shown that ME/CFS is about two to four times more likely to occur in women than men[3], ME/CFS strikes people from every age, racial, ethnic, and socioeconomic group. Some studies show that ME/CFS may be more common in minority groups.
- Common comorbidities with CFS are Fibromyalgia, Orthostatic intolerance, Irritable bowel syndrome, Mast cell activation syndrome, Ehlers Danlos syndrome, Sleep apnea, Food intolerances, Interstitial cystitis, Temporomandibular joint disorder, Chronic pelvic pain, Multiple chemical sensitivity disorder.
<https://drive.google.com/file/d/1SG7hIJTCSDrDHqvioPMq-cX-rgRKXjfk/view>

CFS Symptoms

Chronic fatigue >6 months, post exertional malaise (PEM), unrefreshing sleep and other sleep problems, memory, concentration and cognition problems, pain in the muscles, joints or headaches, light sensitivity and chills, abdominal issues like stomach pain, bloating and nausea, and sinus/ nasal problems, swollen glands tender lymph nodes and sore throat. Some of these symptoms can be made worse by standing up, similarly to POTS.



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Autoimmune disease: occurs when your immune system begins to attack your body. In an autoimmune disease, the immune system mistakes part of your body, like your joints or skin, as foreign. It releases proteins called autoantibodies that attack healthy cells. Longhaulers seem to have developed AI disease due to the immune systems chronic over reactive response.

The most common AI Diseases being triggered in LH's from Covid are:

Rheumatoid Arthritis

<https://www.aarda.org/diseaseinfo/rheumatoid-arthritis-ra/>

Peripheral Neuropathy

<https://www.aarda.org/diseaseinfo/peripheral-neuropathy/>

Lupus

<https://www.aarda.org/diseaseinfo/lupus/>

Sjogrens

<https://www.aarda.org/diseaseinfo/sjogrens-syndrome/>

Vasculitis

<https://www.aarda.org/diseaseinfo/vasculitis/>

Sarcoidosis

<https://www.aarda.org/diseaseinfo/sarcoidosis/>

Amyloidosis

<https://www.aarda.org/diseaseinfo/amyloidosis/>

Of Interest and common, but not 100% considered autoimmune diseases:

Chronic Fatigue Syndrome, POTS/ AI Dysautonomia, MCAS, Fibromyalgia (listed elsewhere)

Diagnosis: Rheumatologist, Endocrinologist, Gastroenterologist and Dermatologist may diagnose your autoimmune disease. Diagnosis is usually based on symptoms and blood tests.

Tests: Antinuclear antibody tests, Autoantibody tests, CBC, Comprehensive metabolic panel, C-reactive protein (CRP), Erythrocyte sedimentation rate (ESR), Urinalysis, biopsies, imaging/ molecular imaging.

- Longhailer's are, according to a recent patient led survey from Oct 2020,, developing autoimmune diseases at a rate of 1 in 5.
- Autoimmune Diseases can affect all parts of the body, just like Covid-19. Covid-19 has left Longhailer's in a chronic inflammatory state which leads to the immune system to attack the body instead of the virus. It is not clear why everyone who is developing Autoimmune Disease post-Covid are not developing the same form of AI disease.

Other AI Diseases coming up in LH testing, but uncommon: complex regional pain syndrome (CRPS), diabetes, chronic inflammatory demyelinating polyneuropathy (CIDP), polymyalgia rheumatica, rheumatic fever, antiphospholipid syndrome, hashimoto thyroiditis, mixed connective tissue disease (especially Ehlers-Danlos Syndrome- note this is genetic and you are born with it), kawasaki disease, interstitial cystitis, guillain-barre syndrome, Giant Cell Arteritis (Temporal Lobe), Eosinophilic Esophagitis, Ankylosing Spondylitis, Myasthenia Gravis, transverse myelitis.



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Fibromyalgia is a chronic disorder which is characterized by widespread pain, tenderness and fatigue. It is difficult to diagnose because most of the symptoms mimic those of other disorders. Fibromyalgia is NOT an autoimmune disease, however it does accompany other autoimmune rheumatic and endocrine diseases.

- Fibromyalgia affects about 4 million US adults, about 2% of the adult population.
- Higher rates of other rheumatic conditions. Fibromyalgia often co-occurs with other types of arthritis such as osteoarthritis, rheumatoid arthritis, systemic lupus erythematosus, and ankylosing spondylitis..
- Sex. Women are twice as likely to have fibromyalgia as men.
- Stressful or traumatic events, such as car accidents, post-traumatic stress disorder (PTSD)
- Repetitive injuries. Injury from repetitive stress on a joint, such as frequent knee bending.
- Illness (such as viral infections)
- More hospitalizations. If you have fibromyalgia you are twice as likely to be hospitalized as someone without fibromyalgia.
- Lower quality of life. Women with fibromyalgia may experience a lower quality of life.
- Higher rates of major depression. Adults with fibromyalgia are more than 3 times more likely to have major depression than adults without fibromyalgia.
- Higher death rates from suicide and injuries. Death rates from suicide and injuries are higher among fibromyalgia patients, but overall mortality among adults with fibromyalgia is similar to the general population.

Diagnosis: A family practice physician, internist, or rheumatologist can diagnose fibromyalgia. In addition to chronic, widespread pain and tenderness, the 2010 diagnostic criteria require that fibromyalgia patients have significant symptoms of fatigue, unrefreshed sleep, and cognitive dysfunction (difficulties with thinking and remembering), along with numerous somatic symptoms. However, fibromyalgia is a diagnosis of exclusion and patients must be thoroughly evaluated for the presence of other disorders that could be the cause of symptoms before a diagnosis of fibromyalgia is made.

Tests: Doctors usually diagnose fibromyalgia using the patient's history, physical examination, X-rays, and blood work. All patients require a thorough history, physical examination, and laboratory evaluation before they are diagnosed with fibromyalgia.

Approximately one third of patients identify a specific event (eg, illness, stress or injury) that precipitated the development of fibromyalgia.

<https://www.cdc.gov/arthritis/basics/fibromyalgia.htm>

https://www.medscape.com/answers/329838-18857/what-are-the-diagnostic-criteria-for-fibromyalgia?src=ppc_google_rlsa-traf_mscpl_kal_eo-pilot_md_us

Fibromyalgia Symptoms

Fatigue, tenderness, pain, sleep disturbances, morning stiffness, anxiety, depression, headaches, problems with thinking, memory and concentration, numbness and tingling in hands and feet, pain in the face and jaw including tmj, bloating, constipation and IBS.



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Mast Cell Activation Syndrome (MCAS): is a condition in which the patient experiences repeated episodes of the symptoms of anaphylaxis – allergic symptoms such as hives, swelling, low blood pressure, difficulty breathing and severe diarrhea. High levels of mast cell mediators are released during those episodes. The episodes respond to treatment with inhibitors or blockers of mast cell mediators. The episodes are called “idiopathic” which means that the mechanism is unknown - that is, not caused by allergic antibody or secondary to other known conditions that activate normal mast cells.

<https://www.aaaai.org/conditions-and-treatments/related-conditions/mcas>

<https://tmsforacure.org/tests/>

Diagnosis: physicians that treat MCAS could be immunology, hematology, dermatology, gastroenterology, pediatrics, neurology, endocrinology and pathology.

Test: serum mast cell tryptase and in urine levels of N-methylhistamine, 11B -Prostaglandin F2α (11B-PGF2α) and/or Leukotriene E4 (LTE4), thorough history for clinical diagnosis based on symptoms.

MCAS is very common in POTS

MCAS Symptoms

Heart: tachycardia, hypotension and syncope.

Skin: itching, hives, swelling and flushing.

Lung: wheezing, shortness of breath and harsh noise when breathing (stridor) that occurs with throat swelling.

GI: diarrhea, nausea with vomiting and crampy abdominal pain.



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Small Fiber Neuropathy: Small fiber neuropathy is a condition characterized by severe pain attacks that typically begin in the feet or hands. Some people initially experience a more generalized, whole-body pain. The attacks usually consist of pain described as stabbing or burning, or abnormal skin sensations such as tingling or itchiness. In some individuals, the pain is more severe during times of rest or at night. People affected with this condition may also have a reduced ability to differentiate between hot and cold. However, in some individuals, the pain attacks are provoked by cold or warm triggers. Small fiber neuropathy is considered a form of peripheral neuropathy because it affects the peripheral nervous system, which connects the brain and spinal cord to muscles and to cells that detect sensations such as touch, smell, and pain. https://medlineplus.gov/genetics/condition/small-fiber-neuropathy/#resources https://www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/peripheral_nerve/conditions/small_fiber_sensory_neuropathy.html https://www.healthline.com/health/small-fiber-neuropathy	Diagnosis: A neurologist treats SFN. Diagnosis is based on history, clinical examination and supporting laboratory investigations. Tests: Skin biopsy, reflex testing, blood and genetic testing, imaging, EMG, nerve conduction studies. • Experts estimate that about 40 million individuals in the US may have peripheral neuropathy of both types—large fiber and small fiber. • Diabetes is the most common identifiable cause of the SFN, but many other causes and conditions are linked to the disease as well. <u>Restless leg</u> syndrome is often associated with small fiber neuropathy, for example, as is having pre-diabetes, <u>rheumatoid arthritis</u>, hepatitis C, Parkinson's disease, chronic kidney disease, and fibromyalgia. • The use of statins, chemotherapy, and alcohol has been linked with SFN. In many patients, no underlying causes are found, however.
SFN Symptoms	Burning, tingling, prickling, short bursts of pain, loss of sensation, urinary or bowel problems, tachycardia, palpitations, dry eyes or mouth, abnormal sweating, sexual dysfunction, sharp drop in blood pressure upon standing (orthostatic hypotension), which can cause dizziness, blurred vision, or fainting.



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Body System	Findings
Heart/ Cardiovascular	Arrhythmia, myocarditis, endocarditis, pericarditis, heart failure, myocardial infarction, ventricular and atrial hypertrophies, mitral and tricuspid valve regurgitation (especially in women), hypertension, hypotension, thrombosis, blood pooling, inappropriate vasoconstriction and dilation, anemia, scarring, cardiomyopathy.
Lungs/ Pulmonary	Pneumonia, Scarring, ground glass opacities, fibrosis, atelectasis, pneumothorax, poor diffusion, pleural effusion, pleuritis, shortness of breath, hypoxia and silent hypoxia, rapid and shallow respirations, exercise intolerance, sleep apnea and hypopnea, pulmonary embolism, asthma and copd "like" issues.
Brain/ Neurological	Stroke, aneurysm, lesions similar to MS, swelling, temporal lobe arteritis, tremors, headaches, coordination issues, brain fog, memory issues, concentration issues, inability to find their words & dyslexia, losing thought mid sentence, confusion, temporary partial paralysis, numbness, tingling, neuropathy, autonomic dysfunction, chronic fatigue, insomnia and other sleep issues, urinary and bowel issues, vision difficulties and disturbances.
Kidneys and Liver/ Renal & Hepatic	Renal & Hepatic insufficiency & enlargement, fat build up, infections, kidney stones, increased urine protein, jaundice, rhabdomyolysis, frequent urination, urinary retention.
Gastrointestinal	Delayed and increased gastric motility, diarrhea, constipation, food and medication sensitivity, nausea, vomiting, bloating, gastritis, eosinophilic esophagitis, growths along the tract should be biopsied.
Immune & Lymphatic System	Autoimmune disease (info in this doc), .swollen and tender lymph nodes. This should be monitored. Lymph Nodes growing in size should be biopsied. Follow imaging with appropriate blood work.
Mental Health	Anxiety & Depression: Pandemic, loss of employment, inability to perform job, attempting to return to job post time off, strained relationships, confined to house, new chronic illness, uncertain future, no current help or cure, upcoming doctors appointments post medical gaslighting. PTSD: Medical gaslighting dismissing our experiences and illness. Hospital experience during acute or post covid.



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Preparing for & Advocating at Doctors Appointments

You are the only person who can truly fight for you and what you need. This is a time that requires you to be strong, driven and persistent. Do not give up, fight for your quality of life and be educated on your conditions. You depend on you.

Documentation	Longhauers have reported over 200 symptoms. Obviously not everyone experiences all of them. Documenting your symptoms every single day is overkill and often adds a lot of stress, which we want to avoid. Doctors will want to know what you experienced during your acute infection, which personally, seems to be completely irrelevant to post-COVID syndrome and symptoms. Have a list of those symptoms. Most importantly, create a list of ALL of your symptoms. You can categorize them in two ways: frequency, as in how often that symptom occurs (1 day a week, a handful of times a month, daily, etc) & severity, as in what symptoms are the worst and affect daily life the most. I prefer the latter as it helps us work towards a solution to the symptoms that diminish quality of life. So again, list of acute infection symptoms, list of all symptoms, then a list of the symptoms that affect you most. Additionally, include a list of your physicians, diagnosis, out of range blood work, medications and tests.
Organization	Put in the time and buy the binder! Some doctors hate this but most LOVE IT. This makes your life and that of your medical providers so much easier. It is an efficient way to locate materials you need on the fly, keep things chronologically (to show trends), and be able to scan/ fax to the office to preload your doctor so your entire appointment isn't spent reviewing, but rather working on solutions. Here are the sections to include: 1- includes the lists you should create under the above documentation section. Additionally, include a list of pending tests/ tests you would like, potential treatments you would like to try and any verbal physician recommendations to circle back to. 2- includes all of your imaging records (MRI, CT, PET, X-Ray, ECHO, EKG etc..) Always ask for a copy of the cd before you leave the facility at the time of the procedure. Most places have a patient portal. Register, and you should be able to print your reports. If not, swing by after a few days and request a copy of the report and include it in the binder. Place a plastic sleeve in the binder in this section to store the imaging cd's. Some doctors like to review it themselves vs go off the report. 3- includes all of your lab work. Companies like Quest and Labcorp have a patient portal where you can review and print off everything. Do this. If you do not use these companies, it is imperative you request copies from the lab or doctors office where you completed this blood work. The same goes for any biopsy results. 4- includes all of your supporting evidence and educational materials. Studies, info-posters, groups, websites, news articles, etc.
Education	Covid is brand new, as are many of the new diagnoses you are being diagnosed with post-COVID to you. YOU must be able to talk about these illnesses with confidence and as firm as an understanding as possible. We have been 5 months ahead of any and all research or announcement coming out of the health organizations. This is important because physicians like to wait until there is scientific evidence from an accredited journal or organization/ university before they take action. The patient led research from our group, body politic and Indiana University is groundbreaking information and the perfect insight into the world of Long Covid. The amount of information also available in groups like ours is a gold mine. Physicians are encouraged to join because they will be exposed to thousands of people;s experiences which will help them become a better clinician. Many physicians have a specialty and stick to it. But with illnesses like the 6 mentioned earlier, the lack of experience and knowledge about them is mind blowing, and you will have to do the work to educate your physician or push them to educate themselves on it. Use your knowledge and documentation to fight for what you need: imaging, bloodwork, referrals to other specialists, diagnosis, treatment/ medications. This section should include: 1- Information about PASC/PCS: Include the patient led studies. Include other studies from JAMA, BMJ, anything else that provides evidence of Long Covid, its chronic effects, the findings in LH's and other conditions it is triggering. 2- Information and studies on the conditions COVID has triggered: POTS/Dysautonomia, ME/CFS, MCAS,

	Autoimmune Disease, Fibromyalgia, Small Fiber Neuropathy, etc. Try to also show the relation to COVID. Encourage the use of the new ICD-10 Codes for further testing and validation. 3- create a list of websites and webinars surrounding Long Covid for your physician and encourage them to watch them should they require more information and access to education on the topic. 4- you no longer need to be part of a trial or study for your Long Covid information to be included and sent to WHO. WHO just released these forms that your doctor can fill out and send in. This is a great idea to do and you should push for it, because the more information they get about the post-COVID issues we are facing, the better the research agendas will be, funding can be better allocated, and it will help provide a more accurate count of how many Longhaulers there are. Here is the website, enter then click download. https://www.who.int/publications/i/item/global-covid-19-clinical-platform-case-report-form-(crf)-for-post-covid-conditions-(post-covid-19-crf-) See resources section for more.
Persistence	If you are not being listened to or believed, or your physician will not accept your issues related to COVID, provide them your documentation and evidence. If they still remain standoffish, FIND A NEW DOCTOR. Your time and health is of utmost importance and someone who doesn't understand the issue, believe it, believe you or simply doesn't care is NOT going to help you in any way. Medical gaslighting is a tremendous issue for Longhaulers and those with chronic illness. Do not stand for it. Demand testing and labs that other Longhaulers are getting (listed in this document) and finding issues with. Pre-COVID and Post-COVID medicine is completely different, and does require some exploration. Early treatment is always key to having a better outcome. Physicians take an oath to "Do No Harm" and there is heavy conversation about this. Some physicians are afraid to deal with us and do nothing, while others are eager to learn and try to help and try things. In the opinion of most, do nothing, does harm. Patients would much rather you try, than do nothing. Demand referrals to other specialists, especially if your insurance requires it. Do not wait, as most specialists are now on months long waiting lists. If your physician does not want to run tests or labs, ask them to document that in your chart and ask for a copy before you leave. It's petty, but it is a way to get them to order the testing, or a reason to report them and find a new doctor. You are not here to make friends, you are here to recover and return to health and regain quality of life, not only for you, but your family, friends and employment. It can also be beneficial to have a doctor you have a good relationship with and who has a good understanding of post-COVID issues to reach out to your other doctors for some "pushing". Many doctors are much more willing to listen to a peer than a patient.



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Advocating In The Workplace

You are struggling at work & find yourself having to take lots of breaks, and calling out sick frequently. You are getting pressured from your superior/ boss/ hr and/ or your relationships with co-workers are suffering. You feel like the quality of your work has decreased.

Recognition	Recognize the situation and be honest with yourself about your struggles.
Be Honest	- Be honest with your co-workers and your boss about what you are experiencing, both at work and in daily life. Sometimes people have no clue what is going on in someone else's life. - Express that your job is important to you and that you always give your best, but lately, your health is having a negative impact on your performance. - Ask your coworkers and boss for understanding. Having an open dialogue and building relationships will be helpful, and maybe others will offer to help you/ lighten the load.
Discuss a plan	- Decrease working hours, work from home, switch shifts, temporary demotion - Ask for accommodations, ie: frequent breaks, less physical work, switching to desk work, a place to sit, allowing water/ food at your workstation - Explore your jobs FMLA, Short-Term or Long-Term Disability and ADA policies. If infection occurs in the workplace, file a workers comp claim asap, as filing post termination or quitting will likely not be possible. - You need to quit. Have an honest conversation and ask if there is any possibility of returning if health improves and ask for a letter of recommendation just in case.

You have been fired after being given accommodations, not having an open dialogue with superiors, or after suspected discrimination for your condition.

What Happened	- Did you have an open dialogue with your boss or HR? If YES, were accommodations made when requested? Did they try to work with you and help with work load and shift changes or location/ workstation changes? If NO, it is worth a try to attempt to explain things now, but it is likely too late to change anything. - If you provided doctors notes, and requested accommodations which were not granted, seek advice from an attorney. - You were given accommodations, but still could not perform your job well or were still missing a lot of time off work.
Benefits	- Did you request FMLA, ST or LT Disability or Workers Comp through your employer? Was it granted? If not, why? Request all the documentation you can get. Seek advice from an attorney. - Were you allowed to use the remaining sick or vacation days? - If you are unable to work, discuss filing for SSDI with an attorney, but be aware there is a requirement of being out of work for 12 months before being eligible. You will need vast cooperation from your physicians for this. - If you can work in some capacity, file for unemployment asap while you are seeking employment.
Discrimination	- Were your requests for accommodations denied? - Was your claim of workers comp, ST, LT or FMLA denied? - Are you a minority in race or gender? - Did you discuss your medical condition at work, and did people make comments about it, accuse you of not being able to do your job as a reason for termination or make any other slanderous remarks about your health condition? - Were you able to perform your job well if given accommodations requested and granted? - Did you have a clean work record? No missed days, never late, completed quality work, no disciplinary issues and were fired? - Did you contract Covid-19 at work and speak out about it, or alert others to negligence or issues surrounding the workplace infection? SPEAK TO AN ATTORNEY! Many can be found on a contingency basis.



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Advocating With Friends and Family

You have a great support system	Let them in. Be vulnerable and open up about your struggles, experiences, fears and hopes. Be honest about how you feel and what limitations you face both physically, emotionally, socially, in the workplace etc. Create a plan for the times where you need a break or need help. Discuss a workload expectation for home life, the kids, chores, etc. Have a plan for days where there will be doctors appointments or testing and help them understand that these events are heavily fatiguing and stressful and recovery time after will be necessary.
Doubtfulness	Some Longhaulers are dealing with dismissiveness, friends and family that are doubtful their issues are covid related or as chronic or severe as they say they are and are putting a lot of pressure on Longhaulers to be "normal" again. While some of this is just ignorance, some of this is denial. No one wants to see someone they care about chronically ill, and it's a long road to acceptance, especially with something like covid which has no rules and no timeline. • Invite these people to spend a few days with you to see what you go through. Take them to doctor appointments if allowed, require them to go food shopping with you or watch you attempt to do household chores. • Show them medical records. Show them the patient led studies, and have them read through some of the group posts and gain an understanding of just how many are affected and suffering and how they are suffering. Millions of people didn't wake up and stage a hoax to pretend to be sick. Have them watch some of the patient PSA's put together and webinars to educate members. • At the end of the day, you will not convince everyone, and more importantly, you shouldn't have to. Drop the dead weight. I know it is easier said than done, but stress is a major contributor to relapses/ flares and chronic inflammatory states. Your main focus is to get back to good health, not only for you but also for your family, your kids, your job and your quality of life.
Grief	It is normal to be experiencing this. People are experiencing grief because: • We are in a pandemic, and they make up the pandemic patients • They have lost pieces or all of who they once were due to their illness • They have lost jobs, hobbies and time in general • They have strained or lost relationships with friends, family, coworkers, etc • They feel like absent parents or even absent children, even to their pets • People have lost their homes and cars they have worked hard to obtain These emotions are natural and what you are feeling is very real. Please discuss these things with a trusted support system. If you do not have one, please seek out someone in the group that you can chat with or a medical professional.
Abandonment	Unfortunately many Longhaulers have faced many kinds of abandonment. They have lost friends and family, including Covid illness being the cause for breakups and divorces, having children removed or less time with them, physicians firing them as patients and work friends or employers themselves walking away. • This is really hard. It is not an easy thing to go through and you need to remember that you are worthy, your feelings and experiences are valid and you deserve better. • Sometimes letting the toxic things go is what is best for everyone. If someone walked away from you in your time of need, they did not have your best interest in mind. Stress is a major contributor to our post-COVID condition and limiting that is the best thing you can do for yourself which goes hand in hand with being your own advocate. • You did not do anything wrong. You did not bring this on yourself, you did not make yourself sick, you do not want to be sick. This illness is out of your control. Focus on your journey back to health.



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Reinfections and Reporting Loopholes

Reinfections

- Reinfections are happening a lot more than you know about, mainly because of a reporting loophole and because many Longhaulers may mistake it as a relapse or flare and fail to get tested.
- People being reinfected vary. Some are patients only 3 months post initial infection, some are a year post initial infection and the rest fall in between.
- Antibodies, according to our study, have little to no significance in reinfection. We are seeing people who still have antibodies, being reinfected. We cannot speak to if this is because of titer levels of antibodies or due to the new strains circulating that make people more vulnerable to reinfection. Keep in mind, some people never even developed antibodies and some of these people never developed antibodies post two vaccinations which is its own topic!

Open Study (results as of 1/11/20):

Read Criteria/ Participate Here https://docs.google.com/forms/d/1uW3JhYXEIcVntoHLyIOf8iMv-Hojc9PyrA2C_3Wx30/edit

- Time between positive tests: 12% under 2 months, 19% 3-4 months, 38% 5-6 months, 19% 7 months, 12% 8-9 months.
- 75% reported having the same symptoms they had the first time, but with some new symptoms added in while 19% reported completely different symptoms.
- 50% said their symptoms the second time were less severe, while 19% said symptoms were the same, 6% said their symptoms were moderately worse and 19% said their symptoms were significantly worse.
- Hospitalization for the second infection increased by 7%
- 31% never developed antibodies after their first infection. 12.5% were 1-4 months out from their positive antibody test and 12.5% were 5+ months out from their positive antibody test when infected a second time. 6% still NEVER developed antibodies after their second infection.
- 6% were positive for antibodies when they were infected a second time.
- 63% were exposed to a known positive case when they were reinfected with 48% stating they were exposed to a high viral load.
- 69% were a longhaueler from infection 1 and remained a longhauler post infection 2, 12.5% were a longhauler from infection 1 but no longer a longhauler from infection 2, 12.5% were not a longhauler from infection 1 but are a longhauler from infection 2, 6% were never a longhauler from either infection.

Moral of the story: double mask, avoid crowds and indoor spaces, wash your hands and act like you were never infected and you are high risk. Now is not the time to be complacent. Especially since about 25% report more severe disease than the first infection and 69% remained Longhaulers after their second infection.

Reporting Loophole

- Genetic Sequencing in the US has severely lagged. It wasn't until November 2020 when this became of interest and sadly, we are only performing 750 genetic sequencing tests from states and local jurisdictions per week and 6,000 per week from commercial labs. That's only 6,750 genetic sequencing tests per week compared to how many covid tests per week? This is not acceptable.
<https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/variant-surveillance/genomic-surveillance-dashboard.html>
- There have been reports of reinfections (only discussing vetted occurrence) since July 2020. No one would listen to these patients. It was not being reported. Reinfections are becoming more and more common, tens to hundreds per day we are seeing in the groups, yet the official numbers represent nothing near this. Why? Genetic sequencing.
- In order to be counted as a reinfection, both of your positive covid tests must have undergone genetic sequencing. This is an issue because this was not being done early on, really even until November, and it is still barely being done now. Many states are not required to perform genetic sequencing, even for suspected reinfections. This should be criminal. This information is imperative to public health, and potentially, the efficacy of vaccines and immunity.
- Additionally, they require that tests should be 3 months apart and have 2 negative tests in between the positives and the genetic sequencing show two different strains. A few things here: 1- you can be reinfected in less than 3 months. 2- your not doing genetic sequencing 3- if there are 3 months and 2 negative tests in between my positive, why does it matter if it is the same or different strain than the first time? Yes, there is talk about viral persistence, but we have NOT been able to provide data on reactivation capable of being contagious and replicating enough to cause positive tests. Everything about this is designed to allow for not reporting cases of reinfection, and that needs to stop...NOW

The state reporting loophole needs to be banned and all tests, if not at least 50% should be undergoing genetic sequencing. This will help prevent the spread of Covid, potentially identify strains that can evade the vaccines, and also potentially link certain strains with disease severity or longhauler issues and symptoms.



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Contributing

Without your help, we get nowhere. All hands on deck!

Research	• Participate and seek out all research opportunities you can find and share them widely in the groups. Research typically takes years if not decades. Longhaulers need immediate help, so by having the masses contribute, the more likely we are to receive help and solutions sooner. • Research opportunities may be local, in person or online. They may be smaller case studies, University or hospital run and can also be run by health organizations like WHO, CDC, NIH or private labs and organizations. • Patient led research has been leading the way and is constantly 5 months ahead of any research or news coming out of the above mentioned bodies. Please contribute to the patient-led studies we and other groups like body politic run. We are sometimes able to get our information from the studies in front of the right people who can do “official and recognized” research and publish their findings. Many times we are introducing new things to them they were unaware of, which speeds up the process. • Go to the resources section in this document and check out the studies page for completed studies and enrolling studies. Please note, not all will be listed, please keep an eye out for others.
Advocacy	• Numerous voices, actions and strong persistence is needed in advocacy. Without advocacy, no one would know who Longhaulers were, that there were prolonged symptoms of COVID, we would not have patient-led surveys, our groups, this group, the Long Covid Alliance, legislative changes and creations, research, media coverage and so on. • There are many ways to be an advocate: Join an advocacy group, provide support to other Longhaulers, help your admin/ mods when they request your help on projects and studies, speak out to the media, speak out about your experiences to others, even if not Longhaulers, speak to doctor and provide them information on Longhaulers/ post-COVID syndrome, post information on your social media, post information on bulletin boards at work or school campus, brainstorm on solutions, create local groups and do things at the local level like contacting your local representatives and senators, your mayors, your local hospital systems and fundraise to help the overall efforts. • It takes a village has now become it takes the world. Lets do this! • CONTRIBUTE TO OUR COVID-COMPETENT PROVIDERS LIST and help other Longhaulers find local doctors who get it and care or visit the list and find one yourself! Contribute a provider to the list: https://bit.ly/COVIDCompetentProviders View the growing list of COVID-Competent Providers https://bit.ly/OFFICIAL-LIST-COVIDCompetentProviders

Assistance Programs

Each state and sometimes each county will have different programs and requirements for the programs. You are encouraged to go to both your county and state websites to locate local resources available to you.

- State or Federal Unemployment
- Food Stamps
- Food Banks
- Rent and Utility Relief and Assistance Programs
- Housing Assistance or Mortgage Deferment Programs
- Credit Card Deferment Programs
- Child care Assistance Programs
- Disability

<https://www.benefits.gov/categories/Financial%20Assistance>

<https://howtogeton.wordpress.com/> (Disability tips)



Current Projects

Long COVID Alliance, Co-Founders	https://longcovidalliance.org/
COVID Competent Provider List	Contribute a provider to the list: https://bit.ly/COVIDCompetentProviders View the growing list of COVID-Competent Providers https://bit.ly/OFFICIAL-LIST-COVIDCompetentProviders
Reinfection Study	https://bit.ly/C19ReinfectionSurvey
Creating a Charity	TBD
Creating a Website	TBD, calling all web developers who would like to volunteer - Covid-19LonghaulerAdvocacyProject.org
Information Posters & Videos	Calling all videographers who would like to volunteer

Resources

Long COVID Alliance- Website Accomplishments, Partners, NIH Letters	https://longcovidalliance.org/ https://bit.ly/LongCOVIDAllianceLaunch
Studies: Completed and Enrolling	https://docs.google.com/document/d/1iyfXbtQdYpd4Y7P2_w2SeVX5R9KtSdSFnAHuPrY-7vk/edit?usp=sharing
Webinars and Videos	https://docs.google.com/document/d/1Co-G_YoQLxaltmxlvZm9s5u244baqV3i_E-c9BWzWl/edit
Websites: Education and Support	https://docs.google.com/document/d/1PfyuRX8dbbk0AA3b13NC-ZGFEe89UWaBHLpzX71mak/edit?usp=sharing
WHO Case Reporting for Physicians (hit download)	https://www.who.int/publications/i/item/global-covid-19-clinical-platform-case-report-form-(crf)-for-post-covid-conditions-(post-covid-19-crf-)
Our Members Advocating in the Media	https://docs.google.com/document/d/1wyXeQSNXNBQKpLE4La8IKO9FbeeBVe1r0fapsM_nyws/edit
Post Covid Care Centers	https://docs.google.com/document/d/1gS5Wbax3RG_ATO41VAD4YWHn2cLeanZKaasoc-sm824/edit
Covid Competent Providers List	Find a Provider https://bit.ly/OFFICIAL-LIST-COVIDCompetentProviders Contribute a Provider https://bit.ly/COVIDCompetentProviders
Top Hospital Systems by State	https://docs.google.com/spreadsheets/d/1PeqtU7v3rtVrx44EP0Zo4K1ribYLZPDO/edit#gid=94700385
Write a Letter List of Congress Members and their contact info Sample letter	https://docs.google.com/file/d/1PVHsxKRDd5Wzd4wCp0xHGuYqTsusMYhA/edit?filetype=msexcel&fbclid=IwAR2VH4g8EVbtuWfrNNvrJEQk7hcwZD4hM7p8fAW68PdHJPZZKGenDCUG1g https://docs.google.com/document/d/18TVpfWfOZp2Qk_qMRDFi_abk9dhYGDlkHAIRR8kfRYlg/edit?usp=sharing
Our Facebook, Twitter, Email and Website (coming soon)	@C19LH_Advocacy C19LonghaulerAdvocacyProject@gmail.com Covid-19LonghaulerAdvocacyProject.org
Information Posters (save and share)	CLAP https://docs.google.com/document/d/1smE_N1ZscJpQP_inCMwrfXa5YhGiZio2nZ38w02wdfs/edit?usp=sharing DI https://docs.google.com/document/d/1c0E9pQJPJOcoTjkGMmHf_hIOWHwBKKcKcdGDZEv3lgEE/edit?usp=sharing SOLVE ME https://docs.google.com/document/d/1phIUVLgAPQYvcUdVRcrsB73f7YbGEw2XUBhPLye8Yrk/edit?usp=sharing



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Let's Work Together, Contact Us!

- Media Requests
- Research Opportunities and Recruitment
 - Member Education
 - Physician Education
 - Webinars
 - Advocacy Efforts
- Questions, Corrections or Additions to this Document

Contact

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